Outcomes Research:

Implications For The Effectiveness Of Nursing Practice

Dr. Gordon DeFriese

Thank you very much for that introduction. I appreciate very much being invited to be with you today to talk with you about an issue of mutual concern.

Let me just say that I am thrilled to see so many people here. You can see that I thought this was going to be a little smaller group and it's exciting to know that in the field of nursing there's a considerable interest in these issues certainly for all of us who are in the field of health services research.

What I'd like to do today is three things and I have a few minutes to do that. I'd like to talk a little bit about what's going on in American health care with regard to clinical outcomes and the quality of care. Then I'd like to talk a little bit about what — so what does this mean for the profession and practice. And then I'd like to say now what does this mean that we should be doing to influence these developments. Now, I understand that my colleague who will speak next will do more of that, but I will try to touch on that just briefly as I close.

Let me just caution you at the very beginning. It is very important to recognize that in this particular area as we discuss these issues there are various points of view, many of them very strongly held. The data in this field is emerging quickly, but the data are contradictory in many cases.

And so therefore it is important to know what kind of interpretation of those data are being rendered. And it's more important to ask who is it that's formulating this particular summary of those data.

Now, I want to share with you briefly an illustration of how important it is to stay alert for these kinds of things. A colleague of mine, whose name actually is the name we've now given our center at Chapel Hill, Cecil Shepps — a few years ago, many years ago in the '50s actually, was returning from a business trip and like all of us had a briefcase full of things he felt guilty about not having worked on and yet at the same time — and he is one of those professors who actually does read his mail.

But, on the other hand he was feeling guilty about this briefcase of stuff, but like all of us he prowled around in the pocket of the airline seat in front of him and found a magazine, which if you also know him he would be very unlikely to ever read much less buy. And this is a magazine called <u>Field and Stream</u>.

What's really interesting about this particular issue was that in this issue — this is in the '50s now — was a review of a book he was surprised would have been reviewed in that magazine. The book being reviewed was the book <u>Lady Chatterley's Lover</u> in <u>Field</u> and Stream.

Now, you'll recall that when this book was first published it was not able to be distributed in this country. It was considered to be so sensitive in its explicit sexual content. So, Cecil decided to read this review. So, he got into the review and the review went something like this:

"This fictional account of the day to day life of an English gamekeeper is still of considerable interest to outdoor minded readers as it contains many passages on pheasant raising, the apprehending of poachers, ways to control vermin and other chores and duties of the professional gamekeeper. Unfortunately, one is obliged to wade through many pages of extraneous material in order to discover and savor these sidelights on the management of a Midland shooting estate."

And then the reviewer concluded with these words. "Despite the interest that this book holds, it cannot take the place of J.R. Miller's <u>Practical Gamekeeping</u>."

Now, I think the point is well made here is that one has to know whose eyes are used for viewing in order to really understand this kind of thing.

Now, the subject we're talking about today has been the cause of widespread public concern about the quality of care available in American hospitals and health care facility, about the knowledge of health care providers including nurses, about the reasons for increasing health care costs and about the availability of health care when it's needed.

All of this has contributed to a situation which has raised doubts about whether it has been justifiable to put health care providers, physicians, nurses, dentists, everybody, on the kind of pedestal we put them on in this country.

In other words, there are now serious concerns about these matters to the extent that newspaper articles are containing the kind of text that we see here. "Seven times as many children in Rutland, Vermont have their tonsils out as in Hanover, New Hampshire only 50 miles away. In one hospital in the same community 19 percent of newborns are delivered with Caesarean section, while at a nearby hospital the rate is 30 percent. Some communities have three times the number of coronary artery by-pass

surgery procedures as other communities in the same state." A very disturbing set of quotations from major newspapers and some minor newspapers around the country.

Then there are the quotations from people in the field that really ought to know whether these statistics are really significant. For example, David Eddy, who's done really outstanding research in this field saying "we don't know what we're doing in medicine." What a quote.

Now, I know in this audience it would go over really big, but for physicians it's very upsetting. Don Berwick, who until recently was the Director of Quality Assurance of the Harvard Community Health Plan saying the embarrassment of our ignorance about the efficacy of health care practices is both blurred and "hard for us to admit and hard for our clients to accept."

Actually I think if we turned the lights down just one more turn you could probably see these. I apologize for how small these may seem. Yes, that's much better.

Then there are some other quotations. For example, Jack Windberg himself saying "the profession lacks consensus on the correct way to practice medicine." That's a pretty provocative kind of statement.

And then we hear quotations like from the IOM itself saying "perhaps one quarter to one third of medical services may be of little or no benefit to patients." Wow, what a quotation from the Institute of Medicine.

And then Dennis O'Leary, who we all became confident in as he gave us nightly broadcasts of the president's health when Reagan was shot, now running the Joint Commission, saying "uncertainty about the most effective diagnosis and therapeutic approaches is pervasive."

And then finally the OTA saying "the link between the process of care and patient outcomes has been established

for relatively few procedures." These are really provocative statements. This is the kind of climate we're existing in right now.

Now, Arnold Relman, who just stepped down as editor of the New England Journal, has been saying that there have been three revolutions since World War II in medicine. The first involved the spread of government and employer sponsored health insurance. The second, the effort to control health care costs in the 1970s and '80s. But, now we're seeing the effort to assess and improve the effectiveness of medical care and thereby improve the quality and perhaps control the costs — which is very different then the way we saw it talked about in the 1970s and '80s — perhaps to control the costs, but certainly to improve the quality of care available to most Americans.

This is a new revolution that we're seeing here and I think that that's why this conference is so exciting. Now, we might say how did all this situation develop? What caused this to occur.

Well, first of all, we had the development of what's called small area analysis — and we'll say more about this in a few minutes — enabling us to look at patterns in the distribution of medical and surgical care, the whole epidemiology of medical care, not just the epidemiology of disease. In other words, looking at the distribution of patterns of the provision of services in a way that we couldn't look at before.

Then we've had studies of variation in the rates of medical and surgical care and concerns about costs and quality, and then efforts to find an association between these rates of performance and selected procedures and measures of the appropriateness of care. People finally getting around to asking the question, if one area like Boston has three times as many surgical procedures as New Haven for a certain condition, what's going on in these

two communities? Is it possible that in Boston too much surgery is being done.

These kinds of questions are now being asked. And now we're being asked to demonstrate the sensitivity of these rates of medical and surgical procedures to intervention. Some kinds of interventions seem to cause these rates to vary.

Now, there were significant early efforts in these regards. This didn't happen over night. I'll just mention briefly several people. E.A. Codman, who is perhaps most famous for the work he did between say about 1910 and 1920 as a Boston surgeon at the MGH where he promulgated his quality assurance system called "The End Result System."

To effect improvement he says "the first step is to admit and record the lack of perfection." He went on to establish some of the first peer review systems and he eventually was sort of cast out and he started his own hospital.

Then J.A. Glover, who did some of the early studies of tonsillectomy, where he said if you take a panel of say 100 patients, young children, and give their records to a panel of pediatricians, 24 percent of them will probably be defined as needing to have a tonsillectomy. And if you take the remainder of those patients and give them to another panel of pediatricians, about 24 percent of them will be found to need a tonsillectomy. And if you take the remainder of that population and then you give it to another panel of pediatricians about 24 percent will be found to need this surgical procedure and so on.

Eventually you can pretty well cover the whole population. And that kind of research was very important in the 1930s, raising doubts about the need, the efficacy, the effectiveness of certain surgical procedures.

And then Limky, a famous public health physician who studied wide variations in appendectomy rates in New York State, was then followed by John Bunker, who know lives in the U.K. since he's married to a U.K. physician, but just recently retired from Stanford, who had done some of the early studies around 1970 of the relationship between the supply of surgeons and the volume of surgery that's actually done.

And then, of course, we're very familiar with the work of Windberg who we'll be talking about a little bit more as I go along.

Now, the means to an end that's important here is that one needs to realize that much of this work could not have taken place that we're talking about in this conference — could not have taken place had it not been for the Medicare Data Set — the data set that was derived from the fact that we had a health care program in this country that covered virtually everyone above the age of 65, therefore giving us a denominator that we could actually work with.

And it was because Jack Windberg, who at the time was Director of Research of the Regional Medical Program in Vermont, who got interested in these data around a couple of years after the passage of the Medicare legislation, they began to put the hard work into developing data tapes that would enable him to do these kinds of analyses that we were able to see what could really happen through small area analysis.

It's very important to realize that what happened at that time was that we first realized the possibility of genuine population based analysis of practiced variations in medical, surgical care. And until that time it probably could not have happened.

The articles that Windberg and Gittleson published that showed data like this — these are the kind of distributional data if you take each one of these dots — they turned out to be u's because my computer was not listen-

ing to my commands.

But, in any event these patterns, each one of them represents a specific hospital service area or market area in Maine. And if you look at certain procedures like hip fracture, ankle fracture, forearm fracture, knee injury and lower back pain — lower back injury, you can see that the distribution of frequency or incidence of hospitalizations for these conditions is very much less variable for a condition like hip fracture, where virtually everyone agrees on what should be done, versus a procedure like back injury, where the chances of knowing what would happen to you in a hospital in Maine with that injury are practically zero.

But, if you had a hip fracture and went to almost any hospital in the state of Maine practically the same thing would happen because most physicians, most people who would examine you would agree on what should happen.

When you look at all of these kinds of procedures the variation is quite extreme. If we look once more at a slightly different way of looking at this, the way Windberg and his colleagues have calculated what they call this SCV ratio, which removes the effects of small sample size, one could use hip fracture as the base rate and look at variability where you have variation many times over for something like back injury.

But, if you use hip fracture as the base giving it a value of 100 percent, you can see that what we're talking about is that there is a tremendous difference between these kinds of procedures. It makes a lot of difference which procedure it is in terms of the certainty with which you can predict what kinds of medical care will be provided.

Now, if we look at what kinds of conclusions have been drawn from small area analysis, the conclusions are very important. Windberg concludes in one of his papers in 1987 that the differences in utilization or differences pro-

vided from one area to another result from decisions providers make after their patients have contacted them. It isn't based upon the theory of medicine or theory of what this condition requires.

It's based upon other factors, many of which are much more subtle then the science of medicine itself.

And then what we see is that these studies have been replicated in other places. I don't have time to review them all in great detail. But, the Canadian studies of Lesley and Noralu Russe have shown that elective surgical rates vary considerably and they've been able to identify what they call the so-called "hysterectomy prone surgical practice style."

In North Carolina, for example, we have a couple of counties that if — many of you are women in the audience. If I were you, I would drive around those counties because the chances of you losing your uterus from one side of that county to the other are very high. And this is what's been found other places.

We have a situation where John Griffith in Michigan has found that the more variation we see in the use of medical procedures, is different then we see for surgical and we find some more variation in admission rates then in length of stay, et cetera. So, that there are a lot of different kinds of studies that have been done.

There have also been studies in the United States where there is great disagreement. Mitchell and Cromwell have found that variation rates in surgery are related not only to the supply and demand, but also to the medical need, ability to pay and substitute sources of care when health status is measured by proxy measures of age and disability.

But the Russe's did another study which found, contradicting that study, that medical need arguments don't hold

when they found that high rate areas of use in Manitoba did not have corresponding high rates of elderly or disabled.

In other words, we're not finding consistency in all of these studies. We're seeing many inner city studies. As I mentioned a while ago, the Windberg et al studies of Boston and New Haven, have found that the numbers of beds per capita in Boston is 55 percent greater then in New Haven and that half of Boston's excess use of hospital care is accounted for by 16 conditions. 22 percent is accounted for by medical back problems, gastroenteritis, heart failure, simple pneumonia and diabetes. All conditions where there are very important factors related to the way in which medical and nursing care is provided that sometimes do not hit one as one looks at these rates of variability.

There have got to be some really strange things going on when you see that the rate of admission in these two cities is very different.

Then we say, which rate is right? Is it right that the rate should be as high as it is in a place like Boston or is it right that it should be as low as it is in a place like New Haven?

In other words, are we talking about a situation where we can tell that someone is not being denied care that ought to get it or are we in a situation where virtually all of the people who get admitted probably do need the care that they're getting and are probably getting that care appropriately?

This has led to very significant research taking place on what we would call the appropriateness of care. I won't take the time to review these studies. But, at Rand Corporation and UCLA a huge team of researchers now for several years have been working on trying to define ways of measuring the appropriateness of care. And these are,

quite frankly, difficult measurement problems.

They involve consensus judgments among practicing professionals in multiple disciplines about specific indications in terms of whether they could justify the admission to a hospital or the performance of a procedure.

The research questions have to do with how large are geographic variations in Medicare Part B covered procedures? Will physicians and hospitals participate in such a study? What's the absolute level of appropriateness for each procedure and to what extent is inappropriate care able to explain these high rates of variation?

And of course they use a several stage procedure which involves the kind of procedure we're seeing associated with these patient outcomes research teams in the sense of meta-analysis of the literature, looking at every conceivable reason why a person might have been admitted, even some that are off the wall. Asking these panels to rate these procedures on a scale that goes from one to nine, with one representing very inappropriate, nine representing very appropriate. And of course, they are very elaborate scoring procedures that go along with these.

But, for example, we've done these kinds of studies ourselves for conditions like hysterectomy. And you start with a set of indications. If you take the various permutations and combinations of reasons why a person might be admitted that include maybe 1,800 separate indications that you ask these panels of physicians to rate.

You could imagine this for nursing care. First defining what the indications are for taking a patient under the care of a nurse and then trying to get nursing professionals to judge these things in terms of appropriateness — inappropriate to appropriate.

When one looks at the data from these studies what pops out at you — what's really dramatic — is that if you take a condition like coronary angiography that 17 percent of the admissions and 17 percent of the procedures performed would be classified by these panels of physicians as inappropriate. But, a procedure like carotid endarterectomy, one of the most frequently done procedures in this country — 32 percent classified as inappropriate. Or upper GI endoscopy, 17 percent. Then if you include all of these ones about which physicians are ambivalent — where they're equivocal — we're talking about a huge volume of medical care, medical and surgical, where there are serious questions being raised.

Now, these data in the hands of the public are dynamite. In our state when it was pointed out that one hysterectomy out of ten is a hysterectomy about which the people who do this procedure day in and day out think there are serious questions, a lot of women get very upset.

Now, the Rand study concluded that if the findings that they have come up with about appropriateness of care can be replicated for other procedures among non-elderly populations, then "a consistent finding of significant inappropriate use would challenge us to find ways of selectively eliminating these practices as a method of substantially improving the quality of care we provided and perhaps simultaneously controlling costs."

In other words, they're saying "if we can demonstrate that, we might demonstrate that some of these procedures don't need to be done at all."

Now, what I would like to do is to suggest to you that some of the work that's going on now, which I think is relevant to some of the things that take place in nursing, that uses this concept of practiced style, which Windberg has been pushing so forcefully, is perhaps one of the theoretical arguments for why we need to look in greater depth beneath these statistics to see if we can explain why these conditions are taking place.

This is a quotation. We won't spend time on here with Windberg. But, Windberg has been pointing out that hospitals in this country — and I think ambulatory clinics will eventually be analyzed this way as well — have a certain surgical or medical signature that reflects the specialties of those who provide the care, the numbers of people who actually do these procedures and the preferences they as individuals have for doing things certain ways.

We found in our hysterectomy studies in North Carolina that there was a lot of hostility to looking at this procedure in any kind of analytic way. Once they got into the data and they began to sit across the table from one another, we were astounded at how little hostility they had toward us and how some of it was reflected to each other.

In other words, some of these physicians would look at each other and say "you do what? You take a uterus out for that reason? I don't understand how you could possibly do that. We repair those in our state — in our area of the state." And they say "well, does it?" He says "well, I do it. It's my specialty. I know how to fix that. You didn't even ask. You just took it out."

And so these kinds of things are really part of the problem. In fact, one of these physicians said "if a middle class woman who plays tennis weekly at the country club has a little problem of leakage on the court, I will take it out."

And so these kind of statements are being made all over America. These are not things that are isolated to one or two places.

The sensitivity of these signatures is the other thing that's been coming out of this research. Windberg has shown that little bits of information cause these rates to vary significantly. He's fond of telling the story of the pediatrician who was chief of pediatrics in a Maine hospital who

had been hounding on his doctors about the number of tonsillectomies and so therefore he at times caused these rates to vary.

This suggests to everyone that there may not be as much hard scientific basis for some of these procedures as we might think. I'll skip on over that.

There are limitations to small area analysis, though. For example, it's difficult to undertake these studies in major metropolitan areas and highly urbanized areas. While these techniques have identified comparatively high use rates, it has not been able to explain them.

Small area analysis has generally not considered possible variations within areas or explored differences in provider practices within communities.

We also have been working on this notion of the theory of clinical uncertainty — the idea that if there exists evidence of clinical efficacy — and I challenge you to think about this in terms of nursing. What do we know really works and how many different studies have been done to show that it works?

Secondly, if we assume that if the data exists there is great variability in physician awareness or acceptance of efficacy data. This is true in nursing and dentistry and pharmacy, et cetera. There is great variability in the awareness of the facts themselves.

And then there's uncertainty that develops in every community about whether the data, as controversial as they may be, really give good guidance. And therefore practice variations are likely to occur. This is the kind of theoretical model that's being tossed around for explaining these variations.

Windberg's approach in trying to do something about this problem is to first determine that the patterns of variation exist and to measure the persistence of these patterns over time, and then to describe the conditions for which the variations are greatest, like back problems versus knee injuries or hip fractures.

Then make the factors known to providers. In other words, let them see these patterns of variation. That in itself causes some change to occur. But, having them get involved in discussing the reasons why variability occurred.

And finally, make outcomes known to patients. If you've seen these recent videotapes he's made, they're provocative, having patients talk about what it was like to have a prosthetectomy or to not have it and to do watchful waiting and to live with some of the side consequences of that.

Now, we know that a lot of people work with patients besides doctors in helping them to understand what to do about these situations. Nursing has a tremendous challenge for itself in many of these areas.

There are many current initiatives that are important that are going on in this field that need to be covered in a conference such as this. There need to be, for example, and there are going on now significant areas to objectively catalog the proper use of existing and emerging approaches to diagnosis and treatment — all of this appropriateness research and technology assessment.

There's a lot of clinical trials on the effectiveness of health care practices. There's a lot of research to understand and therefore to reduce practice variations. This is what we might call outcomes research.

And then synthesis of current research and clinical experience into practice guidelines — something you should look at carefully. How many nurses sit on those guidelines panels? If you don't know the answer to that, you should find out. There's an excellent new report to Congress by the Agency for Health Care Policy and Research

that just came out this week and it details the membership of all those panels.

I mean, one on urinary incontinence. If there's not a prominent role for nursing on there, something's wrong. And I think you should look at those panels.

Secondly, the development and use of clinical and organizational measures to stimulate improvements in quality and appropriateness of care. The whole concern with total quality management can't involve just a bunch of doctors. It's got to involve everybody who works in health care.

Now, AHCPR's medical treatment effectiveness program is a monumental effort and one that is designed to do two things — to determine what works and then to develop some practice guidelines and standards to assess and to assure quality of care. Both of these things are very, very difficult to do and I encourage you to get a hold of that report to Congress, know what they're doing and then be prepared for the future.

What can we expect in the next couple of years? First, I think we can expect a major expansion of information on quality, including effectiveness, efficacy, appropriateness, technical performance, continuity of care, of all health services.

Secondly, the development and continual enhancement of national practice guidelines. And these should be developed not only for physicians, but for everybody else who's involved in patient care.

Third, the growth in rigorous measures of quality and practice guides for using these measures. And finally, widespread dissemination of the above.

Now, one could ask what would a program of research
— you can turn the lights back up now — what would a
program of research in this area involving nursing really

consist of? I think that it should include several things.

One is what do nurses in various settings actually do? I think it should also include a good study, not only of the conditions which occupy a lot of time of nurses, but which may be treated by other people as well, but who else does what nurses do? We need to know what these overlaps and inter-connecting professional obligations are.

The ecology of nursing's domain consensus is very important. Do physicians select patients on different criteria then do nurses for particular forms of therapy and care? Who else cares about what nurses do? That's important to know. Patients and payer constituencies are very important here.

Who and what do nurses need to understand about what they themselves do and what difference do nurses make for what kinds of conditions, under what kind of situations for what kinds of patients and health conditions?

There are different concepts of health, different concepts of therapeutic goals out there and nurses sometimes have very different ones then physicians. The whole notion of what a successful outcome is needs to be looked at carefully. And nurses have a very important role in defining what a successful outcome is.

Physicians sometimes define this almost exclusively in terms of the disappearance of symptoms. And I think that living with these problems afterwards are very important.

So, who needs to know what only nurses can find out? There are several types of studies that need to be done in this area in my view.

And I'll close by pointing out that I think that meta analysis of the extant literature have not been done adequately in this field. Try to find the review articles in this area that are done competently. They're really difficult to find.

The port involvement is very important. If you're not involved in a port and there's one in your institution, you have not done your homework. A nurse needs to be involved in those things. There are nursing questions in every one of them.

The guideline panels, as I mentioned. Fourth, data bases are very important in this field and getting involved in them. Nursing doesn't have enough data bases out there. There's not enough content of practice surveys that are going on. There are not enough microanalytic studies of the efficacy and effectiveness of standard therapies and patterns of care. There are not enough studies of case severity and its impact on nursing outcomes.

These are important agenda items. This conference is important not only to nursing, but to the field of health services research and I congratulate you and the directors of the National Center for Nursing Research for organizing this conference. And those of us who are in the field.

And I have a little bit to do with reviewing articles that get into the formal literature of the field. I encourage you to put some articles out there. There's hardly ever a nurse sends an article to the <u>Journal of Health Service and Research</u>—hardly. And it's really getting too late.

We've got to have a viable field of nursing research in this area. This is the most exciting period we have ever had in health services research.

And people like Norman Weisman and others have created the environment within which this can happen and we deserve — they deserve to have us respond. The money is there. There has never been a better time to petition the agencies that award grant support for the research funds to do this work.

And so I encourage you to get in there and join these teams and join us in this area because I think there's plenty of room for everyone. Thank you very much.